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The objective of this study is to develop, implement and evaluate a volunteer peer support program for women newly diagnosed with breast cancer. This program augments and complements the American Cancer Society's Reach to Recovery Program. Our primary aim is to determine the value of providing a comprehensive, organizationally-specific, peer support program to women beginning at diagnosis and continuing for up to one year. Participants were paired with a trained breast cancer survivor who provided them with ongoing peer support, in addition to specific information and skills to help them navigate the Kaiser Permanente Medical Care Program. Study volunteers received the standard Reach to Recovery training, in addition to a two-day skills training which prepared them to become breast cancer peer support volunteers and advocates. The fourth year of this study was devoted to collection, processing and preliminary analysis of 3- and 12-month data. In addition we developed and administered a volunteer survey; continued volunteer support and supervision; and edited the volunteer training manual. We have obtained a no cost extension in order to finish collection of the 12-month follow-up questionnaires, complete the analysis on the entire sample and write up the results for the final report and for publication.

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FOREWORD

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Annual Report

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Introduction

This report summarizes activities for the fourth year of our study to develop, implement and evaluate a volunteer peer support program for women newly diagnosed with breast cancer. This program augments and complements the American Cancer Society's Reach to Recovery Program. Our primary aim is to determine the value of providing a comprehensive, organizationally-specific, peer support program to women beginning at diagnosis and continuing for up to one year. This randomized controlled trial asks four research questions:

- 1. Does this expanded program improve (a) quality of life with breast cancer; (b) participation with treatment decisions; and (c) satisfaction with care?
- 2. How do patient sociodemographic characteristics influence these outcomes?
- 3. What are the main benefits of this program?
- 4. Does participation in treatment decisions improve quality of life?

Women recruited into the study in five Kaiser Permanente medical centers were randomly assigned to the intervention or control group. Participants in the intervention group were paired with a trained breast cancer survivor (peer support volunteer or "peer supporter") who provided them, beginning at diagnosis, with ongoing peer support along with specific information and skills to help navigate the Kaiser Permanente Medical Care Program. Participants in the control group received the usual support services offered to women newly diagnosed with breast cancer, which in most cases included a referral to Reach to Recovery.

Body

Year Four Activities

The fourth year has been devoted to the collection, processing and preliminary analysis of three- and twelve-month participant data. In addition we developed and administered a volunteer survey. While not originally part of the evaluation plan, the collection of data from project volunteers will allow us to better understand the patient-volunteer matching process and to investigate the potentially beneficial effects of participation in a breast cancer peer support program on the breast cancer survivors (i.e. peer support volunteers) as well as the newly diagnosed women.

Volunteer support and supervision continued through the fourth year. This has included monthly volunteer meetings at all five facilities through December 1997 and telephone support as needed. As noted in previous annual reports, one of the primary tasks of this project has been the training supervision and support of a large and diverse group of women. The sixty-nine volunteers have varied in every possible way. They differed across educational, ethnic, religious and political lines and contact with women has continued to be tailored towards recognition of their individual and group differences.

In addition to regular volunteer support, we organized three special events to thank the volunteers for their work and to mark the end of the project's recruitment phase. These events

provided the opportunity for volunteers to express their feelings about ending work that for many had proved emotionally meaningful.

The fourth year has also included editing our volunteer training manual so that it can be used by others who are interested in developing similar peer support programs. Completion of this process and the editing of the trainer's guide and leader's guide will occur in the upcoming months. After study recruitment ended, we hoped that facility staff who had participated in the research would be able to incorporate the activities of the peer support program into their ongoing job description. Happily, one of the five facilities will continue to offer peer support to newly diagnosed women. In preparation for this ongoing commitment to the peer support program, the breast care coordinator (peer support program facility coordinator) at this site held a volunteer training this winter, in collaboration with the breast care coordinator at another community hospital and the American Cancer Society, using the project's volunteer training manual. Currently, this breast care coordinator supervises (and holds monthly meetings with) a group of peer support volunteers who are both newly trained and who were originally trained as part of our study. In this facility the breast cancer peer support program that was developed as part of this research project is being offered to newly diagnosed breast cancer patients as part of usual care. Unfortunately, the four other sites involved in this research project have not been able to continue the program after the research funding ended. While many of our volunteers in these facilities have expressed the desire to continue their work, the maintenance of such a service requires time and resources. Two facility coordinators have described to us their frustration and disappointment that they have been unable to continue this work on their own.

Below we summarize our evaluation methods and some preliminary results for the baseline and three-month surveys.

Evaluation Methods

The data for this study were collected using three self-administered surveys, completed at entry into the study (baseline), three months, and twelve months after entry into the study (see Appendix for copies of the surveys). The eligibility criteria for the study included women who had: (1) a first diagnosis of ductal carcinoma in situ or any stage invasive breast cancer; and (2) a study contact prior to primary treatment. Every week, during the recruitment period, study coordinators at each facility identified potentially eligible women from the pathology reports and obtained permission to contact these women from their surgeons. If the surgeon approved, the patient was sent an invitation letter (signed by her surgeon) along with a baseline questionnaire and an informed consent form. Upon receipt of these materials, each woman was randomly assigned to either the intervention or the control group. Three months later, she was mailed a three-month follow-up survey. If the survey was not returned within one week, the woman was sent a reminder postcard. If the survey was not returned after an additional week, the woman was sent a second copy of the survey. Finally, if the survey was still not returned after an additional two weeks, a research assistant spoke with the woman by phone and offered special assistance. This process was repeated with the twelve-month follow-up surveys.

In order to determine whether study enrollment the varied by sociodemographic and disease characteristics of the participants, we linked the names of the women who were sent invitation letters to the data in Kaiser Permanente's cancer registry. Using a Chi-square test of association, we investigated whether participation in the study differed by age at diagnosis, race/ethnicity, marital status, stage at diagnosis, and treatment facility within Kaiser Permanente.

Next we determined whether the randomization to the intervention or the control groups resulted in samples with equivalent sociodemographic and disease characteristics. With data from the baseline survey, we used Chi-square tests of association to compare the groups on various characteristics (treatment facility within Kaiser Permanente, age at intervention, stage at diagnosis, race/ethnicity, education level, marital status, employment status, language, living situation, and social support).

We performed an intent-to-treat analysis to determine the effect of the intervention on quality of life at the three-month point. We compared the scores on the Functional Assessment of Cancer Therapy Scales (F.A.C.T.); the physical and mental components of the SF-12 Health Survey; the Center for Epidemiologic Studies Depression Scale (CES-D); and the Illness Intrusiveness Scale for the intervention and the control groups, using t-tests. In order to control for other sources of support and actual participation in the program, we conducted a sub-group analysis comparing the effect of the intervention among four groups of participants. The four groups were those who utilized (1) peer support only; (2) peer support and group support; (3) group support only; and (4) none of the above support resources.

Because we found that the intervention and control group differed on one baseline characteristic (the percentage of women who lived alone) we investigated, using t-tests, whether this variable affected any of the quality of life measures. We also tested to see if this variable interacted with the effect of the intervention on quality of life, using a multivariate analysis of variance model.

Preliminary Results

Overall, 37.8% (n=290) of the women who were sent the invitational packet returned the baseline materials and were randomized into either the intervention or control group (Table 1). The response rate varied by four factors: (1) age at diagnosis, with the older women being less likely to participate than younger women (Table 2); (2) race/ethnicity, with Asian/Pacific Islander, Hispanic, and other/unknown women being less likely to participate than African American and White, Non-Hispanic women (Table 3); (3) marital status, with married and widowed women being less likely to participate than single, divorced and separated women (Table 4); and (4) Kaiser Permanente facility, with some facilities recruiting fewer participants than others (Table 5). Participation did not vary by stage at diagnosis (Table 6).

The response rate for both the three-month and the twelve-month surveys were high. Overall 93.1% of the women enrolled in the study returned the three-month survey. 86.9% returned the twelve-month survey, with an additional 4.1% still pending, which ultimately could

bring the response rate up to 91%. Women in the intervention group were more likely to return both the three-month and the twelve month surveys than women in the control group (Tables 7,8).

The control and the intervention groups did not vary by any of the sociodemographic or disease characteristics that were measured at baseline with the exception of living situation. More of the women in the treatment group than the control group lived alone (31.5% vs. 15.6%, respectively) (Tables 9-18). Upon further analysis, we found that this variable did not affect any of the outcome scales that were measured on the three month survey and that it did not interact with the effect of the intervention.

At three months, there were no significant effects of the intervention on quality of life as measured by the Functional Assessment of Cancer Therapy Scales (F.A.C.T.), the physical component of the SF-12 Health Survey, the Center for Epidemiologic Studies Depression Scale (CES-D), or the Illness Intrusiveness Scale (Table 19) The only significant difference between the two groups was for the mental component of the SF-12 Health Survey, where the control group scored more favorably than the intervention group (Table 19).

In the subgroup analysis, stratifying by use of peer support and support group resources, we found that, among the women who had a peer support volunteer only, the women in the intervention group scored higher than the women in the control group on the overall F.A.C.T. scale, and the Physical Well-Being and the Functional Well-Being components of the F.A.C.T. scale (Table 20). There were no other differences in the effect of the intervention in any of the other subgroups (Tables 21-24). We also found that the differences between the intervention group and the control group on the mental component on the SF-12 Health Survey were no longer significant when stratifying by peer support and support group resources.

Conclusions

We obtained a no cost extension until July 1999 to complete the data analyses, write the final report and manuscripts. Planned analyses include (1) continued analysis of the three-month data; (2) analysis of the twelve-month data; (3) additional subgroup analyses to specify which subsets of patients get most benefit from the program; (4) analysis of the volunteer survey, alone to determine the benefit of participating in the program to the volunteers, and linked to participant data, to better understand the characteristics of a good volunteer-participant match. In addition we will finish editing the volunteer training manual, leader's guide and volunteer coordinator's guide.

Table 1: Overall Response Rates

Sent Invitation Letter	768
Enrolled in Study (N)	290
Enrolled in Study (%)	37.8%

Table 2: Response Rate by Age at Diagnosis

Age	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
Under 40 years	22	9	40.9
40-49 years	150	70	46.7
50-59 years	233	103	44.2
60-69 years	198	67	33.8
70-79 years	132	30	22.7
80 plus years	21	6	28.6

Chi-square (5)=24.0, p<.001

Table 3: Response Rate by Race/Ethnicity

Race/Ethnicity	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
White, Non Hispanic	580	233	40.2
Black, Non Hispanic	63	24	38.1
Asian/Pacific Islander	59	16	27.1
Hispanic	42	9	21.4
Other/Unknown	20	4	20.0

Chi-square (4)=11.7, p=.02

Table 4: Response Rate By Marital Status

Marital Status	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
Single	69	34	49.3
Married	398	144	36.2
Separated	2	2	100.0
Divorced	100	45	45.0
Widowed	85	23	27.1
Unknown	102	37	36.3

Chi-square (5)=14.1, p=.02

Table 5: Response Rate by Facility

Facility	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
Facility A	110	26	23.6
Facility B	158	72	45.6
Facility C	88	26	29.6
Facility D	248	84	33.9
Facility E	164 -	82	50.0

Chi-square (4)=28.0, p<.001

Table 6: Response Rate by Stage

Stage	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
Insitu	112	37	33.0
Local	477	173	36.3
Regional	158	72	45.6
Distant	7	2	28.6
Unknown	10	2	20.0

Chi-square (4)=7.2, p=.13

Table 7: Response Rate for 3-Month Survey

	Control Group	Treatment Group	Overall
	N	N	N
	(%)	(%)	(%)
Returned 3-Month	130	140	270
Survey	(90.3)	(95.9)	(93.1)
Did Not Return	14	6	20
3-Month Survey	(9.7)	(4.1)	(6.9)

Table 8: Response Rate for 12-Month Survey

	Control Group	Treatment Group	Overall
	N	N	N
	(%)	(%)	(%)
Returned 12-month	118	134	252
Survey	(81.9)	(91.8)	(86.9)
Did Not Return	18	8	26
12-Month Survey	(12.5)	(5.5)	(9.0)
Pending Return	8	4	12
	(5.6)	(2.7)	(4.1)

Table 9: Baseline Characteristics: Treatment Group Vs. Control Group

Characteristic	Control Group	Treatment Group	P Value*
	N	N	
	(%)	(%)	
Facility			.99
Facility A	12	14	
·	(8.3)	(9.6)	
Facility B	37	35	
	(25.7)	(24.0)	
Facility C	13	13	
	(9.0)	(9.0)	
Facility D	41	43	
	(28.5)	(29.5)	
Facility E	41	41	-
	(28.5)	(28.1)	

^{*}Chi-square

Table 10: Baseline Characteristics: Treatment Group Vs. Control Group—Stage at Diagnosis

Characteristic	Control Group	Treatment Group	P Value*
·	N	N	
	(%)	(%)	
Stage at Diagnosis			.82
Insitu	15	22	
	(10.6)	(15.3)	
Local	87	86	
	(61.3)	(59.7)	
Regional	38	34	
	(26.8)	(23.6)	
Distant	1	1	
	(.7)	(.7)	
Unknown	. 1	1	
	(.7)	(.7)	

^{*}Chi-square

Table 11: Baseline Characteristics: Treatment Group Vs. Control Group —Age at Enrollment

Characteristic	Control Group	Treatment Group	P Value*
	N	N	!
	(%)	(%)	
Age at Intervention			.10
Under 50 Years	46	34	
	(31.9)	(23.3)	
50-64 Years	62	81	
	(43.1)	(55.5)	
65 Plus Years	36	31	
	(25.0)	(21.2)	

^{*}Chi-square

Table 12: Baseline Characteristics: Treatment Group Vs. Control Group—Education

Characteristic	Control Group	Treatment Group	P Value*
·	N	N	
	(%)	(%)	
Education			.36
8 th Grade or Less	5	4	
	(3.6)	(2.8)	
9 th -11 th Grade	23	12	
	(16.4)	(8.3)	
High School Graduate/GED	50	62	*
	(35.7)	(42.8)	
Some College	40	39	
•	(28.6)	(26.9)	
4 Year College Degree	21	27	
	(15.0)	(18.6)	
Completed Graduate Degree	21	27	
	(15.0)	(18.6)	

^{*}Chi-square

Table 13: Baseline Characteristics: Treatment Group Vs. Control Group—Employment Status

Characteristic	Control Group	Treatment Group	P Value*
	N	· N	
	(%)	(%)	
Employment Status			.26
Working Full Time	68	56	
	(47.6)	(38.4)	
Working Part Time	14	21	
	(9.8)	(14.4)	
Homemaker	8	12	
	(5.6)	(8.2)	
Student	1	0	
	(.7)	(0.0)	
Temporary Medical Leave	9	15	
	(6.3)	(10.3)	
Permanently Disabled	1	1	
	(.7)	(.7)	
Retired	34	39	
	(23.8)	(26.7)	
Not Employed, Looking for Work	7	2	
	(4.9)	(1.4)	

^{*}Chi-square

Table 14: Baseline Characteristics: Treatment Group Vs. Control Group—Language

Characteristic	Control Group N	Treatment Group N	P Value*
	(%)	(%)	
Speak Language Other Than English in Home			.71
Yes	19	17	
	(13.2)	(11.7)	
No	125	128	
	(86.8)	(88.3)	

^{*}Chi-square

Table 15: Baseline Characteristics: Treatment Group Vs. Control Group—Comfort Speaking English

Characteristic	Control Group	Treatment Group	P Value*
	N	N	
	(%)	(%)	
Comfort Speaking English			35
Very Comfortable	17	14	
	(89.5)	(73.7)	
A Little Comfortable	1	4	
	(5.3)	(21.1)	
Not At All Comfortable	1	1	
	(5.3)	(5.3)	

^{*}Chi-square

Table 16: Baseline Characteristics: Treatment Group Vs. Control Group—Living Situation

Characteristic	Control Group	Treatment Group	P Value*
	N	N	
	(%)	(%)	
Living Situation			.003
Live Alone	22	46	
	(15.6)	(31.5)	
Live with Partner, Family, Friends	118	97	
	(83.7)	(66.4)	
Other	1	3	
	(.7)	(2.1)	

^{*}Chi-square

Table 17: Baseline Characteristics: Treatment Group Vs. Control Group—Marital Status

Characteristic	Control Group	Treatment Group	P Value*
	. N	N	
·	(%)	(%)	
Marital Status			.34
Single	11	14	
	(7.6)	(9.6)	
Married	87	71	
	(60.4)	(48.6)	
Domestic Partner	13	12	
	(9.0)	(8.2)	
Divorced	19	32	
	(13.2)	(21.9)	
Separated	2	2	
	(1.4)	(1.4)	
Widowed	12	15	
	(8.3)	(10.3)	

^{*}Chi-square

Table 18: Baseline Characteristics: Treatment Group Vs. Control Group--Close Relatives

Characteristic	Control Group	Treatment Group	P Value*
	N	. N	
	(%)	(%)	
How many relatives do you have that you feel close to?			.27
None	6	7	
	(4.3)	(4.9)	
1-2	34	40	
	(24.3)	(28.0)	
3-5	64	60	
	(45.7)	(42.0)	
6-9	15	24	
	(10.7)	(16.8)	
10+	21	12	
	(15.0)	(8.4)	

^{*}Chi-square

Table 19: Baseline Characteristics: Treatment Group Vs. Control Group—Close Friends

Characteristic	Control Group	Treatment Group	P Value*
	N	N	
	(%)	(%)	
How many friends do you have that you feel close to?			.72
None	4	3	
	(2.9)	(2.1)	
1-2	21	27	
	(15.3)	(19.0)	
3-5	51	56	
	(37.2)	(39.4)	
6-9	28	21	
	(20.4)	(14.8)	
10+	33	35	
	(24.1)	(24.7)	

^{*}Chi-square

Table 20: Results of Scales at 3 Months—Treatment Group Vs. Control Group

Scale	Control Group	Treatment Group	P Value*
	Mean (SD)	Mean (SD)	
Functional Assessment of Cancer Therapy Scales	111.2	110.7	.83
(F.A.C.T.)Overall	(20.2)	(18.3)	
Physical Well-Being	21.7	21.8	.87
	(5.8)	(5.9)	
Social/Family Well-Being	23.3	22.7	.28
•	(4.5)	(4.6)	
Functional Well-Being	20.2	20.8	.33
	(5.6)	(5.3)	·
Emotional Well-Being	16.6	16.7	.78
	(3.0)	(2.9)	
Relationship with Doctor	6.7	6.6	.59
	(1.5)	(1.6)	
Additional Concerns	25.2	25.1	.84
	(6.2)	(5.9)	
Normed-Based SF-12	51.0	48.1	.03
Mental Component	(11.2)	(11.3)	
Normed-Based SF-12	43.4	44.1	.47
Physical Component	(7.0)	(7.4)	
Center for Epidemiologic Studies Depression Scale	10.3	10.9	.58
(CES-D)Short Form	(9.2)	(8.3)	
Illness Intrusiveness Scale	33.9	34.2	.92
	(18.7)	(17.2)	

^{*}t-test

Table 21: Results of Scales at 3 Months—Treatment Group Vs. Control Group —Women Utilizing Peer Support Alone

Scale	Control Group	Treatment Group	P Value*
	Mean (SD)	Mean (SD)	
Functional Assessment of Cancer Therapy Scales	107.6	116.7	.04
(F.A.C.T.)Overall	(18.7)	(15.3)	
Physical Well-Being	20.7	23.3	.04
	(5.6)	(4.5)	
Functional Well-Being	18.9	21.9	.03
	(5.6)	(4.9)	

^{*}t-test

Table 22: Results of Scales at 3 Months—Treatment Group Vs. Control Group —Women Utilizing Group Support Alone

Scale	Control Group	Treatment Group	P Value*
	Mean (SD)	Mean (SD)	
Functional Assessment of Cancer Therapy Scales	114.7	111.0	.68
(F.A.C.T.)Overall	(16.2)	(20.8)	
Physical Well-Being	22.6	20.6	.44
	(4.7)	(6.9)	
Functional Well-Being	20.2	22.2	.45
	(5.3)	(4.4)	-

^{*}t-test

Table 23: Results of Scales at 3 Months—Treatment Group Vs. Control Group —Women Utilizing Both Peer Support and Group Support

Scale	Control Group	Treatment Group	P Value*
	Mean (SD)	Mean (SD)	
Functional Assessment of Cancer Therapy Scales	107.5	105.0	.57
(F.A.C.T.)Overall	(23.8)	(19.8)	
Physical Well-Being	20.8	20.8	.99
	(6.5)	(6.3)	
Functional Well-Being	19.5	19.4	.88
C	(6.3)	(5.6)	

^{*}t-test

Table 24: Results of Scales at 3 Months—Treatment Group Vs. Control Group —Women Utilizing Neither Peer Support Nor Group Support

Scale	Control Group	Treatment Group	P Value*
	Mean (SD)	Mean (SD)	
Functional Assessment of Cancer Therapy Scales	114.7	112.6	.62
(F.A.C.T.)Overall	(18.7)	(14.8)	
Physical Well-Being	22.3	21.9	.77
	(5.9)	(6.1)	
Functional Well-Being	21.5	22.1	.60
	(4.7)	(4.4)	

^{*}t-test



BREAST CANCER PEER SUPPORT PROJECT TWELVE MONTH QUESTIONNAIRE

	completely confidential. Your answers become part of your medical record, or a		•		
	erall, how would you describe the care your breast cancer?	ou received at h	Kaiser Perma	nente to diagn	ose and trea
1	☐ Poor 2 ☐ Fair 3 ☐ Good 4	□ Very good	₅ ☐ Exc	ellent	
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		had or do you Had in past/	plan to have	Do not	Undecided 4
á	ch of the following treatments have you	had or do you Had in past/ having now	plan to have Plan to have	Do not	Undecided 4
a k	ch of the following treatments have you . Mastectomy	had or do you Had in past/ having now	plan to have Plan to have	Do not	Undecided 4
a k	ch of the following treatments have you Mastectomy Lumpectomy (breast conserving surgery)	had or do you Had in past/ having now	plan to have Plan to have	Do not	Undecided 4 □ □ □
a k c	ch of the following treatments have you Mastectomy Lumpectomy (breast conserving surgery) Breast reconstruction	had or do you Had in past/ having now	plan to have Plan to have	Do not	Undecided 4 □ □ □ □
Wh		had or do you	plan to have		
a k	ch of the following treatments have you Mastectomy Lumpectomy (breast conserving surgery) Breast reconstruction	had or do you Had in past/ having now	plan to have Plan to have	Do not	Undecided
a k c	ch of the following treatments have you Mastectomy Lumpectomy (breast conserving surgery) Breast reconstruction Radiation therapy	had or do you Had in past/ having now	plan to have Plan to have	Do not	Undecided IIIIIIIIIIIIIIIIIIIIIIIIIIIIIIIIII

 $_4$ \square Very good $_5$ \square Excellent

1 Poor 2 Fair 3 Good

DECISION MAKING

4.	. 7	To what extent do you agree with the statement, "You should go along with the doctor's advice even if you disagree with it":								
		1 ☐ Strongly disagree 2 ☐ Disagree 3 ☐	l Agree	₄ ☐ Stror	ngly Agree					
5.		To what extent do you agree or disagree with each of the following:	Disagree strongly	Disagree somewhat	Agree somewhat	Agree strongly				
	a.	I understand the advantages and disadvantages of each treatment option:								
		1. Mastectomy								
		Lumpectomy (breast conserving surgery)								
		3. Breast Reconstruction								
		4. Radiation Therapy								
		5. Chemotherapy								
		Tamoxifen (hormonal therapy)								
	b.	I understand why some treatment options were not available to me								
	C.	I had enough time to make my treatment decisions								
	d.	I wish I had had more information about my treatment options								
		I am satisfied with my treatment decisions	. 🗖							
	f.	I usually ask my doctor a lot of questions								
	g.	I have difficulty getting emotional support from my doctor (getting my doctor to understand my feelings)								
	h.	I have difficulty getting the information that I need from my doctor								
6.	Но	w often do you do each of the following?	Never	Sometimes	Often	Always				
		Prepare a list in advance when you visit your doctor	1	2	3 	4				
ļ	b.	Discuss with your doctor any personal problems that may be related to your illness								
(Discuss any problems you had following a treatment plan, such as taking a medicine or following a special diet								
(d.	Call your doctor(s) between visits if you have problems								

7. Ho	ow useful did you find the following	y breast car Very useful	ncer resour Somewhat useful	•	ery Not a		Did not
		1	2	3		4	5
a.	Kaiser Health Education materials (pamphlets, videos, etc.)						
b.	Kaiser psychiatrist, psychologist or psychiatric social worker				[_	
C.	Breast Care Coordinator				[_	
d.	American Cancer Society Reach to Recovery Program			· 🗖	[_	
e.	Kaiser peer support program				[_	
f.	Support group for women with breast cancer			Ċ	[_	
g.	Educational and support services for family and friends					_	
h.	Other				Ε]	
<u>p</u> ;	necking one box per line, please in ast 7 days. Physical Well-Being	dicate how	true each : Not at all	statemen A little bit	t has been fo Somewhat	or you <u>dur</u> Quite a bit	ring the Very much
			1	2	3	. 4	5
a.	I have a lack of energy						
b.	I have nausea	h					
C.	Because of my physical condition, I trouble meeting the needs of my fai			Ц	Ļ		
d.	I have pain						
e.	I am bothered by side effects of tre	atment					
f.	l feel sick						
g.	I am forced to spend time in bed		. 🗖				
h.	Looking at the above 7 questions, he would you say your PHYSICAL WE affects your quality of life?		(circle one 0 1 not at all	,	4 5 6		9 10 nuch so

9. Social/Family Well-Being	Not at all	A little bit 2	Somewhat 3	Quite a bit 4	Very much ⁵
a. I feel distant from my friends					
b. I get emotional support from my family					
c. I get support from my friends and neighbors			_ 🗖		
d. My family has accepted my illness					
e. Family communication about my illness is poor					
 f. I feel close to my partner (or the person who is my main support) 					
g1. Have you been sexually active during the past year? No Yes					
g2. IF YES: I am satisfied with my sex life	Circle o	ne numbe	r) .		
h. Looking at the above 7 questions, how much would you say your SOCIAL/FAMILY WELL- BEING affects your quality of life?	0 1 not at all		4 5 6 7		10 luch so
10. Relationship with Doctor	Not at	A little		Quite a	Very
To. Relationship with Doctor	all 1	bit 2	Somewhat 3	bit 4	much 5
a. I have confidence in my doctor(s)					
b. My doctor is available to answer my questions					
	(circle o	ne numbe			
c. Looking at the above 2 questions, how much would you say your RELATIONSHIP WITH YOUR DOCTOR affects your quality of life?	0 1 not at all	2 3	4 5 6	, ,	9 10 nuch so
11. Emotional Well-Being	Not at	A little	0	Quite a	Very
	all 1	bit 2	Somewhat 3	bit 4	much 5
a. I feel sad					
b. I am proud of how I'm coping with my illness					
c. I am losing the fight against my illness					
d. I feel nervous					
e. I worry about dying					
f. I worry that my condition will get worse					
	•	one numbe		7 ^	
g. Looking at the above 6 questions, how much would you say your EMOTIONAL WELL- BEING affects your quality of life?	0 1 not at all	2 3	4 5 6	7 8 9 very m	9 10 nuch so

12. Functional Well-Being	Not at all	A little bit	Somewh	at	Quite a bit 4	Very much
a. I am able to work (include work at home)						
b. My work (include work in home) is fulfilling						. 🗆
c. I am able to enjoy life						
d. I have accepted my illness						
e. I am sleeping well						
f. I am enjoying the things I usually do for fun						
g. I am content with the quality of my life right now						
h. Looking at the above 7 questions, how much would you say your FUNCTIONAL WELL- BEING affects your quality of life?	(circle o 0 1 not at a	ne number) 2 3 4 II	5 6	7	8 9 very m	10 nuch so
13. Additional Concerns	Not at all	A little bit	Somewha	at	Quite a bit	Very much
a. I have been short of breath						
b. I am self-conscious about the way I dress						
c. My arms are swollen or tender						
d. I feel sexually attractive						
e. I have been bothered by hair loss						
 f. I worry about the risk of cancer in other family members 						
g. I worry about the effect of stress on my illness						
h. I am bothered by a change in weight						
i. I am able to feel like a woman						
j Looking at the above 9 questions, how much would you say your ADDITIONAL CONCERNS affects your quality of life?	(circle o 0 not at all	one number 1 2 3) 4 5	6	7 8 very m	9 10 uch so
Your	Health					
	Excellent	Very Good	Good 3		Fair	Poor 5
14. In general, would you say your health is:						

	5. The following items are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much? <i>(Check an answer for each activity.)</i>						
					OW LIMITE		
			la mushina	Not at al			A lot
	 a. <u>Moderate activities</u>, such as movi a vacuum cleaner, bowling, or pl 			1	2 [_	. 3
	b. Lifting or carrying groceries	ayiiig go				_	
	c. Climbing several flights of stairs						
	d. Walking <u>several</u> blocks				_		
	u. •••u						
16.	During the <u>past 4 weeks</u> have you have regular daily activities as a result of y				s with your	work or o	ther
	a. Accomplished less than you would	d like		1□	Yes 2	□ No	
	b. Were limited in the kind of work of	or other a	ctivities	1	Yes 2	□ No	
17.	During the past 4 weeks, have you ha	ad any o	f the followi	ng problem	s with your	work or o	ther
	regular daily activities as a result of e	emotion	al problems	(such as fee	eling depre	ssed or an	xious):
	a. Accomplished less than you wou	ld like		1	Yes 2	□ No	
	b. Didn't do work or other activities a	as carefu	ılly as usual	1	Yes 2	□ No	
18.	During the <u>past 4 weeks</u> , how much outside the home and housework)?	did <u>pain</u>	interfere wi	th your norr	nal work (in	icluding b	oth work
	₁ ☐ Not at all 2 ☐ A little bit	з 🏻 М	oderately	₄ ☐ Quite	a bit ₅ [☐ Extreme	ly
19.	During the <u>past 4 weeks</u> , how much climited your social activities (like visi					otional pro	oblems
	₁ ☐ Not at all 2 ☐ A little bit	з 🏻 М	oderately	₄ ☐ Quite	a bit ₅[☐ Extreme	ly
20.	For EACH of the following questions, you have been feeling and how thing						e way
How wee	much of the time during the <u>past 4</u>	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
		1	2	3	4	5	6
a.	Have you felt calm and peaceful?						
b.	Did you have a lot of energy?						
C.	Have you felt downhearted & blue?						
d.	Have you felt very anxious or nervous?						

21. Check the box for each statement which best describes how often you felt or behaved this way during the <u>past week</u>.

Di	uring the <u>past week:</u>	Rarely or None of the Time (Less than 1 day)	Some or a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of Time (3-4 days)	Most or All of the Time (5-7 days)
a.	I was bothered by things that usually don't bother me		۵.		
b.	I did not feel like eating; my appetite was poor		Image: Control of the		
C.	I felt that I could not shake off the blues even with help from my family or friends		. 🗖		· 🗖
d.	I felt that I was just as good as other people	. 🗖			
е.	I had trouble keeping my mind on what I was doing				
f.	I felt depressed				
g.	I felt that everything I did was an effort				
h.	I felt hopeful about the future				
l.	I thought my life had been a failure				
j.	l felt fearful				
k.	My sleep was restless				
1.	I was happy				
m.	I talked less than usual				
n.	I felt lonely				
Ο.	People were unfriendly				
p.	l enjoyed life				
q.	I had crying spells				
r.	I felt sad				
s	I felt that people disliked me				
t.	I could not get going				

SOCIAL SUPPORT

22.	questions	netimes look t about the sup o you if you ne	o others for help, fr port that you have. <u>l</u> ed it?	iendship, o How often i	r other type: s each of th	s of support. e following k	Next are inds of su	some ipport
			·	None of the time	A little of the time	Some of the time	Most of the time 4	All of the time
a.		you can count need to talk	on to listen to you					
b.	Someone problem	to give you go	od advice about a					
C.	Someone need it	to take you to	the doctor if you					` □
d.	Someone when you	to help you un need it	derstand a problem					
e.	Someone sick	to help with da	ily chores if you are					
f.	Someone and fears	to share your r	most private worries					
g.	Someone	to do somethin	g fun with					
h.	Someone wanted	to love you and	d make you feel					
23. H a	low <u>many re</u> bout private	elatives and fri matters, can	ends do you have ti call on for help). ((h at you fee l Check one b	l close to (fe	el at ease wi	ith, can ta	lk to nds.)
			23a.	23b.				,
			Relatives	Friends				
	1	None						
	2	1 or 2						
	3	3 to 5						

- 24. Is this more or fewer than before your breast cancer diagnosis?
 - ₁ ☐ More relatives/friends than before diagnosis

6 to 9

10 or more

- $_2$ \square Fewer relatives/friends than before diagnosis
- 3 Same number of relative/friends always had

25. How much does your <u>breast cancer and its treatment</u> currently interfere with different aspects of your life? CIRCLE the number that best describes your present life situation.

If an item is not applicable, circle number 1 (one) to indicate that this aspect of your life is not affected very much. *Please do not leave any item unanswered.*

	<u>Ne</u>	ot Ver	y Muc	h			V	ery Much
a.	Health	1	2	3	4	5	6	7
b.	Diet (e.g. The things you eat and drink)	1	2	3	4	5	6	7
C.	Work	1	2	3	4	5	6	7
d.	Active recreation (e.g. Dancing, sports)	1	2	3	4	5	6	7
е.	Passive recreation (e.g. Reading, listening to music)	1	2	3	4	5	6	7 .
f.	Financial situation	1	2	3	4	5	6 -	7
g.	Relationship with spouse or partner	1	2	3	4	5	6	7
h.	Sex life	1	2	3	4	5	6	7
i.	Family relations	1	2	3	4	5	6	7
j.	Other social relations	1	2	3	4	5	6	7
k.	Self-expression/self-improvement	1	2	3	4	5	6	7
I.	Religious expression	1	2	,3	4	5	6	7
m.	Community and civic involvement	1	2	3	4	5	6	7
n.	Planning for the future	1	2	3	4	5	6	7

Peer Support

26.	In the past year, have you talked to a breast cancancer? 1☐ Yes 2☐ No, I preferred not to	
27.	IF YES, was this woman: (Please check all that a	apply.)
	a. A family member	
	b. A friend	
	c. An acquaintance or co-worker	
	d. A Reach to Recovery Volunteer	
	e. A Kaiser Peer Support Volunteer	
	f. Other (please specify)	_ 🗖

20.	Re	er the past year, now often did you have co covery or Kaiser)? (Please check the box	ontact with that appli	ı a peer supp es.)	ort volunt	eer (either	Reach to
			Not At all	Once or Twice	3-5 Times	5-10 Times	More Than 10 Times
	a.	Telephone calls					
	b.	In person visit(s)					
29.	W	as this:					
	1 [Less contact than you wanted			•		
	2 [•
	з [More contact than you wanted					
30.	if y	you had a Reach to Recovery or a Kaiser P the following areas?	eer Suppo	rt Volunteer,	how muc	h did she l	nelp you
			Very Helpful	Somewhat Helpful	A little helpful	Not at all Helpful ⁴	Does Not Apply
	a.	Get the information you needed					
	b.	Understand your breast cancer diagnosis					
	C.	Decide what treatment(s) to have					
	d.	Communicate better with your doctor					
	e.	Know what questions to ask your doctor					
	f.	Take better care of yourself					
	g.	Find out about and use the Kaiser resources better					
	h.	Deal with job stress					
	I.	Deal with family relationships					. 🗖
	j.	Deal with sexual issues related to breast cancer					

Anything Else?

Is there anything e cancer experience	lse you wou ? If so, writ	uld like to e your co	tell us about tell us about the tell us about th	ut your brea ere.	ast
	, , , , , , , , , , , , , , , , , , , ,		,		

		••••••••••••••••••••••••••••••••••••			
				. 12.11	
•					
*					





BREAST CANCER PEER SUPPORT PROGRAM VOLUNTEER QUESTIONNAIRE

IMPACT OF BREAST CANCER PEER SUPPORT PROGRAM

۱.	The Breast Cancer Pe	er Support Prog	gram has been	valuable for m	ie.
	¹ ☐ disagree strongly	₂ □ disagree	₃ □ neutral	₄□ agree	₅ □ agree strongly
	In what ways?				
2.	Volunteering in this p	rogram has had	a positive effec	ct on my emot	ional health.
	disagree strongly	₂□ disagree	₃□ neutral	₄□ agree	₅ □ agree strongly
	In what ways?				
				.,	
			•		
3.	Volunteering in this plife.	rogram has had	a positive effe	ct on importan	t relationships in my
	₁☐ disagree strongly	₂ □ disagree	₃ □ neutral	₄ □ agree	₅ □ agree strongly
	In what ways?				
			· · · · · · · · · · · · · · · · · · ·		
			 		

т.	The three-day transmit	y was valuable t	o me.		
	¹ ☐ disagree strongly In what ways?	₂ □ disagree	₃□ neutral	₄ □ agree	₅ □ agree strongly
	m what ways:	•			·
5.	The monthly meetings	s were helpful fo	or me.		
	☐ disagree strongly In what ways?		₃ ⊡ neutral	₄ □ agree	₅ □ agree strongly
6.	The program helped n	ne to better nav	igate the Kaise	r Permanente	system.
	₁☐ disagree strongly	₂□ disagree	₃□ neutral	₄ □ agree	
	In what ways?				
7.	The program helped n	ne better comm	unicate with my	doctor	
	disagree strongly		₃□ neutral	₄□ agree	₅ □ agree strongly
В.	The program helped n	ne make decisio	ns about my m	edical care.	
	₁☐ disagree strongly	₂□ disagree	₃ □ neutral	₄ □ agree	□ agree strongly
9.	Keeping a journal was	helpful to me.			
	₁☐ disagree strongly	₂ □ disagree	₃□ neutral	₄ □ agree	₅ □ agree strongly
10.	Overall, on a scale of program?	1 to 10, how ber	neficial to <u>you</u> v	vas your parti	cipation in this
	1=not at all ben	eficial		10=extreme	ely beneficial
	1 2	3 4	5 6 7	9 0 44	·

VOLUNTEER SUPPORT

, do you fe		· · · · · · · · · · · · · · · · · · ·				-			se explain.
·	<u>-</u>								
		•							
				OV	ERA	LL			
on a scal 1=not a				ow wo	uld y	ou rat			ram? mely valuable
1	2	3	4	5	6	7	8	9	10
ning?									
g else?									

ANYTHING ELSE?
b.
·
•

Thank you very much

YOUR BUDDY

Do	o you think you	r relationship with _			helped her to:
4	lindorstand ha	er breast cancer diag	nosis?		
1.		_		_	
	very helpful very helpful	₂□ somewhat helpful	₃ a little helpful	□ not at all helpful	does not apply does not apply
2.	Understand he	er treatment options?	•		•
	₁☐ very helpful	₂ somewhat helpful	₃☐ a little helpful	□ not at all helpful	₅ does not apply
3.	Get a second	opinion?			
	₁☐ very helpful	₂☐ somewhat helpful	₃ a little helpful	not at all helpful	₅ does not apply
4.	Communicate	more effectively with	her doctor?	•	
	₁☐ very helpful	₂ somewhat helpful	₃ ☐ a little helpful	□ not at all helpful	₅ ☐ does not apply
5.	Know what qu	estions to ask her do	octor?		
	₁☐ very helpful	₂ ☐ somewhat helpful	₃ ☐ a little helpful	₄☐ not at all helpful	₅ does not apply
6.	Take an active	role in her health ca	re?		
	¬□ very helpful	₂ ☐ somewhat helpful	₃ ☐ a little helpful	₄□ not at all helpful	₅ does not apply
7.	Find new sour	ces of support?			
	₁☐ very helpful	₂☐ somewhat helpful	₃ ☐ a little helpful	□ not at all helpful	₅ does not apply
8.	Find other type	es of help she neede	d (e.g., rides, bat	py-sitting)?	
	₁□ very helpful	₂ ☐ somewhat helpful	₃ ☐ a little helpful	₄□ not at all helpful	₅ does not apply
9.	Find out about	and use Kaiser Perr	manente resource	es?	
	₁□ very helpful	₂☐ somewhat helpful	₃ ☐ a little helpful	₄☐ not at all helpful	₅ ☐ does not apply
10	. Deal with job s	stress?			
	□ very helpful	₂☐ somewhat helpful	₃ ☐ a little helpful	↓□ not at all helpful	₅ □ does not apply

11. Deal with fam	illy relationships?				
₁☐ very helpfu	l ₂□ somewhat help	oful ₃ □ a little he	lpful ₄❑ not at al	l helpful ₅ 🗖 do	es not apply
12. Deal with sex	cual issues related	to breast cance	r?		
₁☐ very helpfu	l ₂□ somewhat help	oful ₃ □ a little he	lpful ₄ □ not at al	l helpful ₅ 🗖 do	es not apply
13. Please discus	ss any of the abov	e:			
		ACTIVITIE	S		
How often did yo	u offer the followin	ng types of supp	ort to your budo	ly?	
14. I shared my e	xperience of breas	st cancer with m	v buddv.		
₁☐ not at all	₂☐ once or twice	₃ □ 3-5 times	₄☐ 6-10 times	₅□ 11 or more	times
15. I visited with	her.				
₁□ not at all	² □ once or twice	₃ ☐ 3-5 times	₄ □ 6-10 times	₅□ 11 or more	times
16. I talked with h	ner on the telephor	ne.			
₁ □ not at all	² □ once or twice	₃☐ 3-5 times	4 □ 6-10 times	₅ ☐ 11 or more	times
17. I went to lunc	h, dinner or coffee	with her.			
₁☐ not at all	₂☐ once or twice	₃ ☐ 3-5 times	4 □ 6-10 times	₅□ 11 or more	times
18. I sent a greeti	ng card to her.				
₁□ not at all	₂☐ once or twice	₃ □ 3-5 times	₄ ☐ 6-10 times	₅□ 11 or more	times

		another physica	i activity with ne	r.
₁◘ not at al	l ₂□ once or twice	₃ □ 3-5 times	4 □ 6-10 times	₅ ☐ 11 or more times
20. I drove her	somewhere.			
₁□ not at all	l ₂□ once or twice	₃ □ 3-5 times	4 □ 6-10 times	₅ ☐ 11 or more times
21. I took her to	the doctor.			
₁□ not at al	₂□ once or twice	₃ □ 3-5 times	4 □ 6-10 times	₅ ☐ 11 or more times
22. I went with	her to get a prosthe	esis.	•	
₁□ not at all	2 □ once or twice	₃ □ 3-5 times	4 □ 6-10 times	₅ □ 11 or more times
23a. I did some	ething else with her	(please specify:).
				₅ ☐ 11 or more times
23b. I did some	ething else with her	(please specify:).
₁◘ not at all	l ₂□ once or twice	₃ □ 3-5 times	4 □ 6-10 times	₅☐ 11 or more times
		·		
		THE MATC	Н	
04 Danie 4late	1.41-4			
				were a good match?
	k that you and ch so ₂□ somewh			
	ch so ₂□ somewh			
₁☐ very mud	ch so ₂□ somewh			
₁☐ very mud	ch so ₂□ somewh			
₁☐ very mud	ch so ₂□ somewh			
₁☐ very mud	ch so ₂□ somewh			
₁☐ very mud	ch so ₂□ somewh			
very muc	ch so ₂□ somewh	nat ₃□ not rea		
very muc	ch so ₂□ somewh	nat ₃□ not rea		

. What types of things made it easy to develop a relationship with her?													
												·	
. What type	es of thin									with h	er?		
					 -								
Reflecting	g on youi ideration	r expe wher	rience we m	e with	this I budd	buddy ies wi	, are th vol	there luntee	othei ers?	things	s we ne	ed to ta	ake
						- Hub							
0. <i>Overall</i> , h	ow usefi	ıl do y	ou th	ink th	is pro	ogram	was	for yo	ur bu	ıddy?			
	1=not a	t all u	seful					10)=extr	remely	useful		
	1	2	3	4	5	6	7	8	9	10			
1. Anything	else?												
				···									
			••·· <u>·</u>										
													